

REVIEW

Overcoming barriers to a successful transition from pediatric to adult care

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Abstract

As life expectancy for people with cystic fibrosis (CF) has increased dramatically, so has the need for a guided, structured transition from pediatric to adult-focused care. A formalized transition program allows for seamless transfer of patients between providers, helping to ensure continuity of care, and avoid potential declines associated with inconsistent medical care. New CF Center guidelines issued by the CFF strongly recommend that each center establish a transition program for age-appropriate transition to an adult CF clinic. In this article, we explore the remaining barriers to establishing a transition program in a CF Center and offer examples of several successful models. We describe CFF-sponsored and other initiatives that exist to support centers in establishing a transition program and discuss the need for ongoing research in this area.

KEYWORDS

CF R.I.S.E, cystic fibrosis, transition

1 | INTRODUCTION

For individuals and families facing childhood onset chronic illness, there are at least three critical points in their illness—time of diagnosis, adolescence, and transition to adult care—each of which must be handled with great care.¹ One population that has been at the forefront of the discussion regarding the need for structured transition has been cystic fibrosis (CF). Decades ago, medical care for those with CF was focused on the goal of ensuring survival to adulthood. However, given significant advancements in CF medical therapy, survival in the CF population has steadily increased with the current median survival age of 41.6 years,² and many patients will now spend more years under the care of providers trained in adult subspecialties rather than pediatric subspecialties. The health of people with CF has improved markedly over the last decade. In 2015, adults 18 years of age or older comprised 51.6% of the United States CF population,

compared to 29.2% in 1986.² These statistics magnify the importance of having good, collaborative transition procedures to avoid gaps in care, and to prepare people with CF and their families for Adult CF programs.

The importance of a planned transition from pediatric to adult care has long been a topic of major concern to many health care providers. The desirable time for transition (generally between ages 18 and 21) coincides with many other significant life events, including graduating high school, beginning college, launching a career, and becoming legally responsible for personal decisions. This stressful period in a young adult's life can lead to poor health outcomes, as patients struggle to cope with many simultaneous changes compounded by difficulties with access to care.^{3,4} It has been shown that compared to age-matched peers, young adults who grow up with a chronic health condition achieve milestones later in life or not at all, including attaining a job or having a serious relationship.^{5–7}

Studies have demonstrated that if systematic approaches are not utilized, individuals with chronic illnesses face almost insurmountable barriers to a successful transfer—from hospital logistics, such as location of clinics, to poor communication between pediatric and adult providers, to parents who refuse to relinquish primary responsibility for disease management.^{1,8–12} Further burdening transition is patients' perception that they are receiving poor quality of care from internists who are unfamiliar with "pediatric" diseases.^{1,8–10} These barriers may lead to problems with fragmented care by three distinct but interrelated processes; patients not seeking care until a serious problem arises, not managing chronic symptoms to slow rate of decline, and avoiding engaging in preventative care.^{3,13} This may be an unintended consequence of the family-focused care provided in pediatrics that can limit education, independence, and attainment of self-management skills for the adolescent with a chronic disease.¹² Consequently, there is a clear need for guided transition of patients from pediatric to adult care.

The goal of a planned transition is to improve quality of life, maximize independence, and minimize interruption in care as a patient moves from a pediatric to an adult subspecialist.¹⁴ It is crucial to note that this process occurs over a number of years, not as a single event in a patient's life. In the absence of dedicated efforts for transition, patients are simply transferred to an adult provider when they age out of being cared for by a pediatric provider. Often such a transfer may occur at a time of rapid clinical deterioration or even sometimes in the absence of a patient's agreement if the transfer is delayed. Timing of transfer needs to be defined *a priori* but also remain somewhat flexible and correspond to the adolescent's maturity level and current health status.¹⁵ A planned, structured transition is most appropriate for providing uninterrupted care and support for the young adult with CF. The CF Foundation has strongly advocated for this approach since 2000, requiring all CF centers with more than 40 adult patients to establish an adult program. In 2008, recognizing the unique problems facing adults with CF, the CFF Center Committee recommended that all CF Centers transfer at least 90% of their patients to adult providers by age 21. This approach has stood strong, and now nearly all accredited US Pediatric CF centers have an affiliate adult program¹⁶ or are partners with an Adult CF Center. Despite this, however, considerable variation continues to exist in the structure of transition (or lack thereof) from center to center.^{3,4,17}

1.1 | Overcoming barriers to transition

Living with a chronic disease diagnosed in childhood necessitates trust in the medical team. Leaving the familiarity of the pediatric CF team that has provided care for many years can be a anxiety-provoking concept for patients and families. Introducing the idea of transition as a normal, healthy part of becoming an adult is paramount and best discussed longitudinally beginning prior to adolescence, preferably right after diagnosis.¹⁰ By discussing the concept of a planned transition early in the life of a CF patient, the expectation is set that the patient will achieve adulthood, will become independent from his parents, and will become a functioning member of society. In fact,

patients who are involved in a structured transition program indicate a stronger degree of satisfaction with their pediatric center as well as a higher perception of their health status.⁸ Transferring to an adult care program has been shown to give patients a sense of optimism about the future and self-worth as an adult participating in society.¹⁸

Despite the known benefits of transition, barriers still exist on the patient, family, and provider levels. Education of the patient with CF about disease-specific manifestations, complications, and treatment is necessary to ensure self-management skills. In one study, while knowledge of nutrition and lung health was relatively high among selected adults with CF, less certainty was documented for reproductive and genetic issues,¹⁹ irrespective of patient age, socioeconomic status, or disease severity. Clearly, insufficient knowledge about fertility and reproductive health may lead to poor decision making regarding family planning and vulnerability to sexually transmitted infections.²⁰ A survey of CF adults indicated unmet needs for education, particularly on the topics of new CF therapies, ways to cope with symptoms, and the uncertainty of the future.²¹ On the caregiver level, parents, accustomed to providing all aspects of care to their child with CF, may be reluctant to give up control and watch their child struggle to find independence, especially if poor adherence has the potential to lead to negative health outcomes. The pediatric providers may also contribute to a delayed transition, fearing a decline in the level of care provided after transfer to an adult team.¹¹ A close partnership with adult providers is also critical to ensure confidence in continuity of care and prevent delayed access to a new provider from being a reason for patient's health decline. While in the past, adult pulmonary fellows often had limited exposure to CF patients, the aging of the patient population has resulted in exposure of many more of these patients to adult pulmonary trainees. Finally, an absence of post-transfer outcome measures reported by the adult CF programs accepting these patients also hinders the improvement process surrounding development of a transition program.

1.2 | Approaches to transition

Ultimately, no single process for transition will work in all healthcare systems, and it is the responsibility of each CF Care Center to determine the approach that will best meet the needs of their patient population and fit within the constraints of their healthcare system. Some tools to facilitate transition include joint newsletters,⁸ transition appointments involving both adult and pediatric providers,^{8,15,22} tours of adult facilities,^{8,10} and medical health summaries,²³ among others. Importantly, education about CF must start early and focus on the patient as well as the family, and education must be ongoing and repeated periodically to ensure that the adult with CF is well-informed and capable of self-management.^{12,23–25}

Several tools, both general and CF-specific, exist to guide providers and centers in developing a transition program. Got Transition (<http://www.gottransition.org/>) and the Center for Health Care Improvement is a cooperative relationship between the Maternal and Child Health Bureau and The National Alliance to Advance Adolescent Health, designed to facilitate transition for any chronic

health condition.¹⁴ Got transition provides six core elements of health care transition to serve as a guide for patients and providers. The STARx program (<http://www.med.unc.edu/transition>) supplies readiness assessments and self-management tools to identify areas of knowledge and skill deficits among patients ages 12 and older and provide age-appropriate education.^{26,27} The Transition Readiness Assessment Questionnaire (TRAQ) was validated as a tool to facilitate the measurement of skills deemed necessary for a successful transition of youth with special health care needs, including domains on self-advocacy and self-management.^{28,29} Beginning in 2010, Gilead Science and CFF collaboratively worked on a CF-specific transition tool known as CF R.I.S.E. Led by a panel of experts in CF and transition, this working group created a program that combined knowledge assessments, goal setting, and responsibility checklists for use by the CF team in guiding transition. Further details about CF R.I.S.E. are discussed below.³⁰

1.3 | Building a strong relationship

Ultimately, a successful transition program depends not only on the efforts of the pediatric providers educating patients and families and advocating for transitioning to the adult care, but also on adult care teams ready with knowledge about the disease, appropriate personnel, and bandwidth to welcome these patients into adult clinics. This is certainly facilitated when a single pediatric center transfers most of its patients to a single adult center on the same campus. In this case, providers share the same medical records and frequent communication is feasible. This model allows for bidirectional flow of information, including feedback to the pediatric provider about the preparedness of an individual patient.³¹ Often, a joint "transition clinic" is available, where a patient and family can witness direct turnover of the care from one specialty team to another. In reality, though, many patients do not continue to be followed at the same center for both pediatric and adult care, whether this is because of facilities on different campuses, relocation of the patient, or the decision to pursue treatment elsewhere. In these cases, additional options include a "health passport"³² maintained by the patient, or a "warm handoff"³³ where the sending physician communicates directly with the receiving physician, typically over the phone, beyond simply sending records. It is important to note that the transition process does not end with the transfer of the patient from pediatric to adult care; rather the adult team assumes responsibility for continuing to prepare the young adult for independence. Successful cross-talk between the pediatric and the adult teams will give the new providers detailed information about where educational deficiencies or limitations in responsibilities lay for continued attention after the transfer.

1.4 | Outpatient versus inpatient

Transitional care-related work predominantly, and appropriately, takes place in the ambulatory setting. The majority of pediatric and young adult CF patients are admitted infrequently to the hospital; in addition, it is also best to have such discussions when a patient is

feeling at his or her baseline so additional anxieties are not added to a patient during a time of acute illness. However, an inpatient stay, particularly beyond the initial acute phase of an admission, can provide an opportunity to spend an extended and more focused time working on skills necessary for the transitioning patient. The ambulatory visit can be very busy with the multi-disciplinary team addressing all the clinical and mental health needs of the patient, making it challenging to add yet another assessment with educational support. The inpatient setting can provide time for a patient to work on assessments like CF R.I.S.E and benefit from real-time remediation by qualified individuals. This can also be an opportunity for the patient to work on identifying a primary care provider, organizing appointments, and strengthening skills of self-management and self-advocacy. Particularly for those CF patients who are admitted frequently to the hospital and for those staying in the hospital for the duration of the IV antibiotics, this is an opportunity for the multidisciplinary care team to make inroads in transition related matters for patients in need of additional support.

1.5 | Transitioning the parents

As noted above, excessive parental involvement or "overparenting" may be a barrier to a successful transition.^{30,34} In a Danish study of 58 patients and their parents, 40% of patients aged 18-25 still lived with their parents and their parents played a daily role in the CF management.³⁵ It is therefore important to include parents in the transition process. After the patient has reached age 18, they may opt against including their parent in further discussions of their health care, but in our experience, patients tend to encourage the ongoing involvement of their parents. Parents can be involved by encouraging adolescents to take responsibility for cleaning and managing equipment, calling for refills, writing down questions for the clinic appointment, or notifying team members when an issue arises. The Responsibility Checklists included as part of CF R.I.S.E. (as described in section 2) are designed to help identify the person responsible for various aspects of CF care within each caregiver-patient dyad. These can serve as a tool to facilitate a conversation about transitioning responsibilities.

2 | CF R.I.S.E.

Many individual CF centers have transition programs, yet no one specific program is widely adopted.³⁶ In addition, most CF transition programs are missing an objective way to determine patients' knowledge about the disease, their independence in managing their disease and their readiness to move to an adult care provider. CF R.I.S.E. (Responsibility. Independence. Self-Care. Education) was created to address these issues.¹⁷

The CF R.I.S.E. program objectives are to provide people with CF and the care team with tools that can be flexibly implemented to help manage transition and transfer. It introduces the need for a gradual, purposeful transition of responsibility from support person to patient

over time, and helps facilitate communication among pediatric and adult care teams, patients and caregivers. It complements existing transition efforts with tools that could be considered as a quality improvement (QI) initiative. CF R.I.S.E. was developed in collaboration with a multidisciplinary team of CF experts and is sponsored by Gilead Sciences. The modules are written at a 5th grade reading level, with program material and tools having been approved by the CFF Education Committee. In early 2015, after conducting a pilot study, the toolset and material were launched nationally for patients 16-25 years.³⁶ The implementation of CF R.I.S.E. at 10 centers has shown that the program has the potential to address the deficits in transition.³⁶ A process evaluation of CF RISE implementation based on the Consolidated Framework of Implementation Research (CFIR) was done. A total of 95% of the CF healthcare providers from the 10 sites that participated in the pilot project completed an online survey about their experiences 6 months after initiating the program. Providers reported that CF RISE facilitated communication with patients and family. All providers rated the program as valuable with 60% finding the program very or extremely valuable. Ninety-five percent felt the program could become a sustainable part of the clinic, and 91% felt that it was somewhat or completely likely that they would be using the program 1 year from now. Providers also appreciated the flexibility of the program. CF healthcare providers positively evaluated CF RISE during its initial implementation period.¹⁷ CF R.I.S.E. comprises a series of CF education and skills assessments on various topics designed to identify areas that need more focus and support and allowing the patient and care team to work together to develop a personalized and focused plan. Knowledge assessments ensure that conversations are occurring about all areas of CF care. In this way, education deficits are identified and addressed.¹⁷ In 2016, a toolset was developed for 10-15-year-old patients and their families. The modules were written at a 3rd grade reading level and were approved in September 2016 by the CFF Education Committee for dissemination to CF Centers. Figure 1 shows a suggested implementation approach to incorporating CF R.I.S.E. into the clinic.

2.1 | Other CFF initiatives

In 2008, a study of US CF centers demonstrated that less than 25% of centers typically provided educational material about transition to patients and families, and only 18% had designed specific programs to foster education and readiness skills.²³ The CFF has put into place multiple tools to rectify this situation, including CF R.I.S.E. (as described in section 2), PACE (Program for Adult Care Excellence) awards and equivalents for pulmonary and non-pulmonary adult providers, and the Learning and Leadership Collaboratives (LCC). The PACE award provides up to three years of mentorship and academic salary support for individuals interested in advancing the care of adult patients with CF, which has been used by some trainees to design and institute a transition program. Through initiatives like the DIGEST (Developing Innovative Gastroenterology Specialty Training) Program, the CFF is doing its part to attract academicians trained in gastroenterology. Similarly, CF Related Diabetes demands the expertise of an endocrinologist who understands this complication, as well as bone disease and other adult specific complications. Mentorship programs funded by CFF in Physical Therapy, Nutrition, Social Work, nursing and others, are helpful in attracting and training adult CF team members essential to a program caring for adults. LLC programs sponsored by the CFF utilize the Dartmouth Institutes Clinical Microsystems Academy curriculum, focusing on quality improvement, meeting skills, leadership, and management skills. For these collaboratives, QI teams from 6 to 12 different institutions are assigned QI coaches and conduct weekly phone meetings, periodic conference calls, and quarterly face-to-face collaborative meetings to learn QI strategies, tools and methods, and to report on progress. This tools could be crucial for a center seeking to develop a transition program.

2.2 | Experiences from 3 centers

As noted previously, each CF Center needs to work within the constraints of their healthcare system to formulate a transition process.

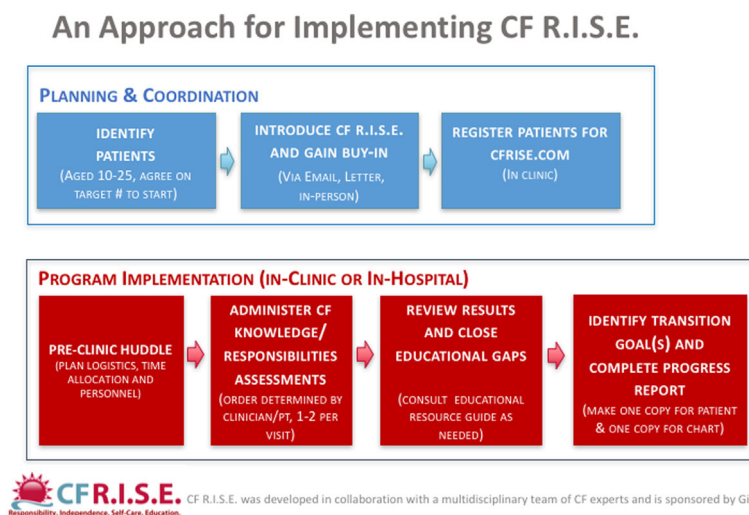


FIGURE 1 A suggested approach for the implementation of CF R.I.S.E.

To illustrate how tools can be adapted within an institution, we offer the examples of how our own centers formulated transition programs.

2.2.1 | University of North Carolina at Chapel Hill (UNC)

Through the ONECF LLC2, the UNC CF Center created a multidisciplinary team involving members of the Pediatric and Adult CF Programs, patients and parents, to address the transition process. The focus is on optimizing communication among members of the pediatric and adult CF teams, engaging patients and their caregivers to better understand the patient perspective regarding transition, and adoption of the CF R.I.S.E. program. This particular approach was selected in order to have a definable measure of success in increasing health literacy among our patients.

At UNC, transition is discussed at the time of diagnosis. As a child grows older, increasing attention is paid to the education of the patient and family in terms of independence and self-management skills with children encouraged to have at least part of their clinic visit without the parent in the room beginning in early adolescence. Adolescents are also asked to identify a goal that they would like to work on before the next meeting. Beginning at age 16, adolescents are registered for CF R.I.S.E. by a dedicated transition coordinator, who also troubleshoots the program and serves as a point of contact between clinic visits. The transition coordinator role is a position unique to this program and one critical to its success. Feedback is provided to the pediatric providers about educational successes and deficiencies identified by the CF R.I.S.E. modules. Members of the multidisciplinary team facilitate education by answering questions that are raised by completion of the knowledge assessments and responsibility checklists. Patients in the transition pipeline are discussed during a monthly transition meeting that involves multidisciplinary team members from both the pediatric and adult care teams; at this time, incorporating patient and family wishes, an optimal time for transfer is recommended, typically at least 1 year after high school graduation. The team also discusses the preferred adult provider, based on personality, gender preference, and clinic day, among others.

As the transfer time approaches, patients are met in the pediatric clinic by the multidisciplinary adult care team and are offered a handbook that includes contact information and clinic-specific information about the Adult Care Clinic. Patients and families may choose to tour the adult clinic, the inpatient adult facilities, or both. Typically, a patient and their family will meet with adult care team members 1-2 times prior to the formal transfer. At the designated last pediatric visit, the pediatric CF nurse and/or transition coordinator facilitates an appointment in the adult clinic, with the goal being <8 weeks between the two visits to minimize the chance of a significant health issue interrupting the planned transition. After the patient is seen in the adult clinic for their first visit, feedback is provided to the pediatric CF care team. As a QI measure, health related outcomes will be tracked for a year following the transfer to the adult center.

2.2.2 | Boston Children's Hospital (BCH) and Brigham & Women's Hospital (BWH) CF center

A multidisciplinary QI initiative led to the implementation of a new transition program at the combined BCH and BWH CF Center in collaboration with ONECF LLC2. This program offers a unique and effective transitional care model.

Part of a hospital-wide transitional care initiative, a cohort of our Adult CF Program operates within a young adult program offering ambulatory and inpatient care from adult providers to those up to 30 years of age, while care to those older than age 30 is provided at BWH. The program is part of a multi-disciplinary inter-hospital, inter-health care collaboration, established to support the age appropriate medical, surgical, and transitional care needs of all young adult survivors of congenital or acquired pediatric diseases. It is a model that demonstrates an emphasis on ambulatory and inpatient transitional care preparation along with age appropriate care. Within this framework, introduction and discussion of the transition process at our CF Center begins at time of diagnosis, whether through newborn screening, diagnosis later in childhood or adolescence, or upon transfer to our CF center. A transition policy was developed for the CF center making the program and its transition processes transparent.

2.2.3 | Phase I

Pediatric caregivers introduce the adult CF program at the earliest encounter (as noted in section 2.2.2) and at other opportunities (eg, Family Education Night) to alert patients and families of the existence of the transition process. By age 14, or sooner for some patients, the parents will be asked to leave the room for a portion of the visit with the full transition process starting at age 16.

2.2.4 | Phase II

The transition process starts with identification of patients turning age 16. A member of the CF multidisciplinary transition team (clinic RN's, CF center NP's, or pediatric social workers) is assigned as "transition coordinator" for each patient. A letter and/or email is sent out to the family and patient to alert them of the upcoming process. The transition coordinator is responsible for guiding the patient through the transition process and documentation of an up-to-date checklist which also allows any member of the team to step in and work with the adolescent before the multidisciplinary team presentation to the adult CF team. The transition coordinator works with providers, patient, and family during clinic visits, and hospitalizations when appropriate and provides feedback. The tasks on the checklist include completion of a minimum number of CF R.I.S.E. modules while the multidisciplinary team works together with each patient to perform a comprehensive review of all aspects of their care. As the patient approaches the end of this second phase, an adult pulmonologist is identified when appropriate, Health Care Proxy and HIPPA forms are signed and timing of transfer is discussed.

2.2.5 | Phase III

A patient's transfer to adult care is brought up for discussion at quarterly meetings held jointly with members of the pediatric and adult multi-disciplinary teams in attendance. Individual patients are generally discussed around 18-21 years of age, but in some exceptional cases up to age 26. A timeline toward eventual transfer is determined and an adult provider is chosen to meet with the patient prior to transfer to the adult CF program. The transition process continues as the adult team resumes work where the pediatric team left off and toward mastery of the skills necessary for an adult with CF.

2.2.6 | University of Michigan, Ann Arbor, MI (U of M CFC)

The U of M CFC transition program was developed in 1980. Its goal was to assure patient follow-through and to reduce the incidence of patients dropping out of the health-care system.⁹ The U of M Transition Program consists of two phases.⁸

2.2.7 | Phase 1. preparing for transition

The transition process is introduced to patients and families at time of diagnosis or at their first visit to the center. As patients get older, a shift from interacting with parents to interacting with patients is done with a focus on reeducation about the disease process. Independent visits are offered and encouraged. Intervention with the adolescents and families to help improve adherence to treatment and resolve any conflicts is done. There is a focus on anxiety and depression screening and intervention for all adolescents and parents. One of the center priorities is having the adult CF team as an integral part of the annual newsletter and family education function to demonstrate collaboration between the two programs. The pediatric team evaluates patients for transfer readiness through mid to late teenage years and re-introduces the transfer process to patients. In addition, patients who are turning 18 years of age are periodically discussed in the joint Pediatric and Adult CF Programs monthly meeting which is attended by the two CF Center Directors, CF Center coordinators and the transition coordinator (the pediatric center social worker).

2.2.8 | Phase II. active transition process

At 16 years of age, the pediatric pulmonary team discuss the process with the patient and family. The adult pulmonologists are reviewed and a choice of one is made. A patient ready for transfer is reviewed in the monthly pediatric-adult CF meeting. Medical records are reviewed by the adult pulmonologist, followed by an appointment in the pediatric clinic attended by the pediatric and adult teams to provide opportunities for interaction between the medical teams and patients and families. A tour of the adult inpatient and outpatient facilities is offered prior to the transition to adult care. If the patient and family are not ready after this joint clinic session, the session is repeated up to three times.

Even though the transition program was established in 1980 and went through assessment and revision twice,^{9,8} the program lacked an

objective way to evaluate patients knowledge about CF and readiness for transfer to the adult program. To address these deficiencies, CF R.I.S.E. was adopted to provide patients, families, and the care team with tools that can be flexibly implemented to help manage transition and transfer. It complements the existing transition program with the most needed tools.³⁰ CF R.I.S.E. has been used since 2012 with more patient/families satisfaction with the transition process.

At U of M, there is a transition program for all patients with genetic or chronic childhood diseases. This program is in the early phase of development compared to the CF transition program. It covers technology dependent patients, sickle cell disease, muscular dystrophy, and others. This transition program studied the CF transition process and CF R.I.S.E. at the U of M and used some of the knowledge assessments and responsibility checklists after modifications.

2.2.9 | Transitioning across the healthcare spectrum

Beyond CF, between 500 000 to 750 000 adolescents with special health care needs will transfer annually to adult care teams.³⁷ Medical advances have led to an increase in adult survivors of chronic illness, much like CF. Each survivor of a congenital or pediatric acquired chronic disease brings its own set of challenges to the transition process and while there is increasing attention to the development of appropriate transition programs, there is still much work to be done.¹⁴ The knowledge attained from the literature on this subject is heavily populated by our experiences from CF. The early push and financial support from the CFF toward development of adult CF care centers decades ago highlights the role CF has played in this field.

However, the field of transitional care medicine and research is also moving forward nationally. Given the lack of consensus and the limited agreement on successful outcome measures, leaders in the field and those taking part in the Interdisciplinary Health Care Transition Research Consortium (HCTRTC) have identified a list of outcomes for researchers in the field to validate with quality of life as a target outcome measure.³⁸ The need for alternative outcome measures for those with cognitive disabilities underscores the challenges facing transitional care efforts across the chronic disease landscape. Models of inclusive, hospital-wide initiatives are beginning to take shape to address the challenges faced by free-standing children's hospitals across the country. The Center for Youth and Adults with Conditions of Childhood (CYACC) at Indiana University has an outpatient consultative model while the Transition Medicine Clinic has a Primary Care Model focus. Children's Mercy in Kansas City has challenged primary or specialty care programs to join a hospital-wide transition plan. Figure 2 suggests an age-based model for guiding CF patients on expectations for transition during adolescence; this guideline can be modified for individual patients.

2.3 | Outcomes

Limited data currently exists regarding health outcomes following transition, including mortality, acquisition of new bacterial species, and change in pulmonary function status after transition. One study of 68

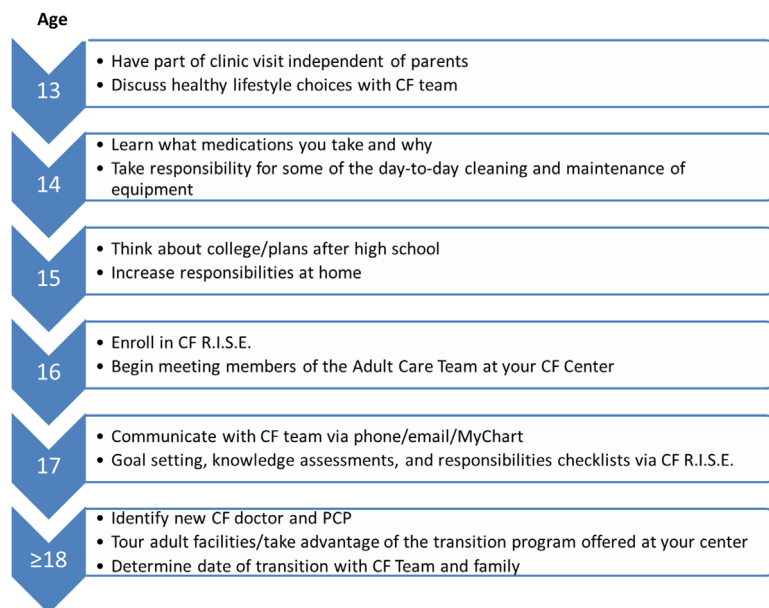


FIGURE 2 Suggested transition guideline for patients based on age

patients followed for 1 year before and after transition to an adult center showed a non-significant decrease in lung function and no changes in sputum microbiology or requirement for antibiotics.¹⁵ Another study used propensity-matched scoring in a cohort of patients from the CF Foundation Patient Registry and showed a less rapid decline in lung function 2 years after a cohort of age-appropriate patients who transitioned to an adult clinic versus those who did not. There were no significant differences in BMI, hospitalization, and use of home IV antibiotics.³⁹ A more recent study performed structured interviews with 45 recently transitioned patients, and noted that although there was significant individual variability, the mean FEV1 and BMI did not change 1 year after transfer. Importantly, there was a sense of optimistic acceptance about the future.⁴⁰ As more centers are becoming engaged in the creation of a formalized transition program, it would behoove the community to study post-transition outcomes

further, including BMI, FEV1, pulmonary exacerbations, and patients lost to follow-up after transfer.

2.4 | Special considerations

Certain circumstances deserve special consideration to determine when, and if, transfer to an adult care team is appropriate. One such case is that of the adolescent CF patient who is actively dying. Most caregivers would agree that it would be in the best interest of the patient and family to remain with the pediatric care team throughout this difficult process, with reassessment occurring if the patient's health changes. Patients who are under consideration for lung transplant should also be considered separately. In many centers, multidisciplinary care for a transplanted patient is provided by a team of professionals that is distinct from the CF

TABLE 1 Suggestions for best practices for transition

Patient level	Begin discussions of transition early in life
	Develop a road map in preparation for transition readiness, disease knowledge, and skills assessment to share with patients and families
	Create a personalized medical summary to ensure seamless continuity of care, especially where an electronic medical record is not shared by pediatric and adult programs
CF team level	Create an open and transparent dialogue between the pediatric and adult CF programs
	Develop a working transitional care policy at all levels of the multidisciplinary team (include input from patients and parents)
	Create a registry of eligible patients and a plan to discuss them periodically
	Identify outcome measures to monitor progress and success, including establishment of best practices and communication among pediatric and adult care teams
Institutional level	Seek institutional leadership buy-in
	Collaborate with other hospital programs focused on transition
	Invest in EMR systems with patient access to personal health records and built in transition tools

Care team. In these circumstances, one must weigh risks and benefits to the patient unnecessarily enduring two transfers, the first from pediatrics to adult care team and the second from the adult care team to the transplant team. Children with special health care needs outside of CF, including mental health, are another distinct population that may not fall clearly into a single transition model. Depending on local resources and specialty providers, it may best benefit the child and the family to have a mix of adult and pediatric care providers. Communication is key to facilitate these transitions. In any scenario, the authors advocate for ongoing education and preparation of the patient with CF to ultimately assume responsibility for their health care.

3 | SUMMARY

The ongoing successes of personalized medicine, acute and chronic medical therapies, quality improvement initiatives, initiatives targeting adherence, multidisciplinary care models, patient and family involvement, and more, have led to significant increase in median life expectancy of CF patients and an increasing number of adult CF patients.² This change in the landscape of the disease underscores the importance of coordinated transitions of care. Caregivers of those with CF continue to be at the forefront for developing models of transitional care support for individuals living with complex, multi-system, chronic illnesses. Pediatric CF programs need to strengthen their focus on preparing adolescents and young adults in order to facilitate continued success and stable health outcomes in adult CF programs. Our combined experiences have made it clear that a comprehensive transitional care framework is essential to successfully transition a patient from a pediatric to an adult CF program. They also illustrate the flexibility of creating a transition program that adapts to the larger healthcare environment within individual institutions. Table 1 provides a set of guidelines that were crucial in the development of a transition program at the three sites represented in this article; other centers seeking to develop a transition process may use them to initiate discussions.

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